



Commonwealth of Virginia *Office of Governor Glenn Youngkin*

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Office of the Governor

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Governor Youngkin Announces Addition of Two New Disorders to Virginia's Newborn Screening Program

RICHMOND – Governor Glenn Youngkin today announced the addition of two new disorders to the Commonwealth's newborn screening program, which helps detect a variety of rare, life-threatening conditions in infants. Beginning March 16, Spinal Muscular Atrophy (SMA) and X-linked Adrenoleukodystrophy (X-ALD) will join a screening panel of metabolic and genetic disorders that range from the more well-known Cystic Fibrosis to many relatively obscure conditions that can cause severe sickness, physical or mental disabilities, even death, if not diagnosed early.

"While these disorders are rare, the ability to diagnose and treat them early is life-changing and possibly life-saving for these babies," **Governor Youngkin** said. "Every child born in Virginia deserves the best possible start in life, and our dedicated scientists and nurses in the newborn screening program have committed their lives to making sure that happens."

Virginia's newborn screening program is a partnership between the Department of General Services' Division of Consolidated Laboratory Services (DCLS) and the Virginia Department of Health (VDH). The program was first mandated in 1966 and is required by law for all babies born in the Commonwealth except when parents have a religious objection. DCLS tests dried blood samples derived from pricking the baby's heel 24-48 hours after birth to screen for 33 disorders, once the two are added this week. Additionally, the program includes screening for Critical Congenital Heart Defect and a hearing test to identify congenital hearing loss, both of which are completed before the baby leaves the hospital. Babies who fail the initial hearing screen are tested for congenital Cytomegalovirus (cCMV), a viral infection that can lead to hearing loss.

"Scientific advances allow us to continue to build on Virginia's newborn screening program, which started with screening for one disorder in 1966 and has grown to include the identification of thousands of babies each year who are either born with a disorder or could be a carrier," said **DGS Director Joe Damico**. "This program is an extraordinary example of agencies working together to improve the lives of Virginia's residents."

"For parents of a baby identified on a newborn screen with one of these disorders, VDH newborn screening nurses are able to assist them as they seek appropriate follow-up diagnostic testing and referral to consultants," said **Acting State Health Commissioner Colin M. Greene, MD, MPH**. "By screening for these disorders shortly after birth, and linking families with specialists and resources, we are protecting the health of Virginia's youngest residents by promoting timely diagnosis and treatment for optimal outcomes."

SMA, which affects approximately one out of every 11,000 U.S. births, can impact a baby's ability to swallow, breathe, sit and walk, and without treatment could lead to premature death. X-ALD renders certain fats unable to be broken down in the body, and their buildup affects the nervous system and adrenal glands. Symptoms vary widely for the disorder, which disproportionately affects males. Six of every 100,000 babies born in the U.S. will be diagnosed with X-ALD.

The newborn screening lab at DCLS performs 4 million newborn screening tests on approximately 100,000 samples received annually. The lab operates seven days a week, including holidays, to deliver timely results to new parents. VDH newborn screening staff follows up on abnormal test results for more than 20,000 infants each year, making sure the babies are referred to physician specialists to receive the care they need.

"We are excited to get started screening for these two new disorders, as we know the real impact it will have on the lives of those families affected by these conditions," said **Dr. Denise Toney, Director of DCLS**. "The state lab is committed to building our newborn screening program as proven tests and treatments are developed."

The Virginia Newborn Screening Advisory Committee recommended the addition of SMA and X-ALD to the Commonwealth's newborn screening panel after they were included nationally on the Recommended Uniform Screening Panel (RUSP). The RUSP is a list of disorders the Secretary of the Department of Health and Human Services recommends for states to screen as part of their newborn screening programs based on evidence regarding the potential benefit of screening, the ability to screen for the disorder, and the availability of effective treatments.

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